



Unheard Voices: interviews with deafened people

Simon Pridham
Interviewed by Pam Blackman

British Library ref. C1345/29

IMPORTANT

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Interview Summary Sheet

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Collection title: Unheard Voices: interviews with deafened people

Interviewee's surname: Pridham

Title:

Interviewee's forename: Simon

Sex: Male

Occupation: Driver

Date and place of birth: 1976

Date(s) of recording: 15th March 2009

Location of interview: The City Inn Hotel, Bristol

Name of interviewer: Pam Blackman

Speech to Text reporter: Mirella Fox

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Interviewer's comments:

[Track 1]

This is Pam Blackman, and I am interviewing Simon Pridham, for the Unheard Voices project and we are in Bristol and it is Sunday 15th March 2009. And the Speech-to-Text reporter is Mirella. Okay. Simon, to start off with, just kind of to get you remembering and to spend as long as you like really, if you can just talk about your childhood, first of all perhaps if you give us your date of birth, and your full name and your occupation? That sort of just to kind of set on the record.

Ok. I am Simon Paul Pridham, my date of birth is the 14th, of the 8th, 1976 and I work for a textiles reclamation company.

Okay. And where were you born?

I was born in Exeter in Devon.

Okay. Do you, your father's and mother's occupation? If known.

Yes. They jointly own a rentals company in Cyprus where they live.

Okay. As I say just to start off with, or to spend as long as like on really, can you talk a little bit about your childhood, any memories that immediately come to mind?

Yeah. Childhood memories that come straight to mind are just of fun; great times at school. I was always a bit of a cheeky chap at school, but like to get on with the work. Spending holidays in Cornwall, with my family, we were a close knit big family. Obviously my immediate family and grand parents and aunties and uncles; so we used to spend quite a lot time together. So those are the good memories I have from my childhood.

Did you have a lot of cousins, the same age?

Yes, a couple that were close. In fact one of my cousins was ten days older than me, that's my cousin Donna, but we used to spend a lot of time with her family, her sister, myself and my sister. And then we had other cousins who lived in Cornwall that we didn't see that often.

But would get together during the summer holidays. So yes, close knit family and some good times.

And have you, would you still describe yourself as a close-knit family?

Yes. The family have spread out and about a bit. As I said my parents live in Cyprus, also my auntie and uncle now live there. But I still see my cousins. I have still got family who live in Cornwall who I see every now and then. And obviously some of the family on the my wife's side now, so yes, family is important. But I have got no children of my own.

Okay. So were you brought up in Exeter? Is it in Exeter or –

Yes, I was born in Exeter and lived there until about 7, 8 years ago, then moved about 8 miles outside when myself and Sharron got our first place together. And now we live just on the Devon/Cornwall border in a village called Lewdown, out in the countryside, it is very nice.

I am sure, yes.

Yes.

How long, well when did you leave school?

I left school in 1992. And straight from school I went to work doing an NVQ in retail management at Debenhams, mainly with Champion Sport, their sports group that were part of Debenhams. So, I didn't go to college or to uni. I just preferred to go, because sport retail is what I wanted to do. So that is what I went straight into.

Did you stay in that line of work?

Yes I stayed in retail until about 2000, but then got a little bit frustrated with the day-to-day workings of retail. And so I then changed jobs, I went to work for a furniture company and as the area sort of warehouse manager. So just tried a different tact. So but yes, that was good to do to change. But yes, retail was for the first sort of ten years of my working life was good, yes.

Okay. And your wife is she from very much the same part of the country?

Yes, she is, she was born in Exeter as well and we met through an ex-girlfriend of mine who was her best friend, so yes, again she was from Exeter. Yes.

[05:31]

So, was there ever an issue at that stage about, was your wife already deafened then?

No she wasn't. Sharron, I met her as I said through my ex girl friend and shortly afterwards met her family and Sharron's dad was a deafened man. Obviously, at that point I didn't really know a lot about it. Although when I was at school I had done some work with deaf children at the Exeter Deaf School, which wasn't too far from my high school. So I had some idea of deaf people, I have met them.

Can I just ask you was that an interest, had you or was it a chance?

Yes it was a chance. One of our teachers had set up a just a thing where we could go and meet some deaf children, work with them, see how, you know, how their life was and obviously being close to our school it was quite handy that we could just pop up. So we did as part of a project, just meeting deaf children, and there are also a couple of deaf children who went to our main high school. Obviously had hearing aids so they had some hearing. So I did interact with deafened and profoundly deaf people at school. So, that gave me a little bit of knowledge and a bit of confidence in talking to deaf people and I found it quite easy to talk to Sharron's dad John. So it was quite good. At that point Sharron had full hearing. She suffers with a condition called NF2 which is neuro fibromatosis, type 2, which is brain tumours on the hearing nerves which cause deafness. She was diagnosed in 1993 which was a year after we had met and then started to lose her hearing from probably about '95 I think. So we have been together for a long time, since we were about 15, 16 years old, so I have lived with her and been with her through the loss of her hearing, so yes.

Okay. So, did her father does her father suffer from the same?

Yes, he has actually now passed away but he also had NF2. At that point we didn't know it was an hereditary illness because a lot wasn't really known about it. But Sharron also has a brother who has a NF2 as well. And they were advised eventually by a doctor to have an MRI scan to check to see if they had NF2 and that's obviously when it was found out.

Is it something which, if it is found out about, can be treated?

Yes. I mean, in the days of when Sharron was diagnosed, it was very much you have NF2, you will need an operation, you will become deaf. And have facial palsy, which obviously for someone who is 17 years old and obviously being a lady who, looks are very important to Sharron, that was very devastating. Since that time, the progression has come on and genetics have moved on, and now children can be tested quite early even you know as young as one or two with a blood test to see if they have got the faulty gene. Sharron, when Sharron was diagnosed it was pretty much at that time that children could have a, from about the age of 12, 13 years old to see if they had NF2. As for the treatment of it, it just depends on the size of the tumour. Obviously surgery is one option. If the tumours are small enough they can be removed without much problem. And also radiotherapy is another option to go down. Unfortunately, for Sharron, although she is younger than her brother, she had bigger tumours, and they were right on the edge of the size where radiotherapy wouldn't really work although she did have radio surgery to see if it would help. So it, at this moment it is more you know treatable.

[10:18]

What is your perceptions you have been there when during this process?

Yes.

You know, how what is your experience of the, how the system works?

Yes. It was quite - I think we, lucky to a certain degree that Sharron's dad was diagnosed originally with NF2 so we had some idea of what it entailed. I think, for instance, when we went to see the doctor when Sharron was diagnosed, she was told by the doctor that she would have to have surgery. But we had already looked into radiotherapy and that was

something he didn't even mention. So we were lucky in the fact of we knew a little bit about it. So I think that for other families it would have been a bit more difficult. It was a difficult time. Obviously I hadn't been with Sharron that long. But I have sort of found it quite easy to deal with for being a hearing partner. My focus has always been on supporting Sharron. She has been worried about how I would feel about it, you know, would I want to leave her because of this horrible thing that has happening to her but I have never looked at it like that, it has always been a part of our lives and our time together. So, it is just for us it is normal and an every day thing to deal with.

Yes, can I just get -- when Sharron's hearing loss first began, was she how old was she?

She was, probably '95, so, about 18, 19 when it started to go down.

You have known each other, well, a few years?

Yes.

You were both very young.

Yes, yes

So.

It was again because Sharron's dad had had a similar thing happen to him, him losing his hearing gradually until he had his operations and lost his hearing, so it was something we kind of knew how to deal with. Although obviously it was still hard to. But I would say that for me personally, it has been okay. For Sharron it has been difficult but we have managed.

Yes

[12:42]

Has it affected your, as you say, it is normal it is part of your normal life, but do you think it, do you ever feel that your life, you know, has been, not compromised but –

Yes I see what you are saying. Yes, I think if I am honest, you sometimes obviously think how much easier your life could be. And I get frustrated on the communication side as well as Sharron does and everybody I am sure is like that. You want things to be easier. For instance, Sharron doesn't socialise a great deal because obviously she feels having a bad hearing loss and now completely deaf, that being in a social atmosphere is very difficult for lip reading and communication and I understand that. That frustrates me sometimes because I feel she is missing out on a lot. So, there are, yes sometimes you think, Oh, yes, life could be so much easier, but that's very rare that I think that and we just deal with the situations that it comes.

Do you tend to socialise sometimes or separate on your own?

Yes, we do. When we first got together, we socialised a lot with friends. Obviously this is when Sharron had a good and full hearing. She doesn't have many friends, I think because of the progression of her hearing loss, having operations and so on, she felt comfortable when she was with me and preferred my company to making new friends. We have a lot of friends through bowls that I play, a similar age and our next door neighbour is also very friendly. So there are pockets of friends but certainly not as many as I have on my own. So I do tend to socialise a fair bit on my own. You know, it worries me sometimes; I am going out leaving Sharron on her own. And I feel guilty for that. Quite a lot. But she doesn't mind and she will do stuff at home. So it makes me feel she re-assures me it is okay to do that.

It is probably difficult for you to say, but it could be that her personality doesn't need so many friends anyway or it could be part of obviously partly her hearing.

Yes it is a mixture of the two, yes. Sharron doesn't mind that she hasn't got lots of friends. That's just as you say, that's part of her personality, that's part of how our lives have developed. So, yes. She is fine with that, I know that. Yes. But it is hard when I have quite a lot of friends.

You work full-time, does Sharron?

Yes. Yes, she works for full-time. She works for a sports company in Exeter. She was the assistant manager on the shop floor, but when her hearing got to too low she then transferred

to the stock room manager there and that's what she is currently doing, but yes she still works full-time.

[16:11]

You have talked about your bowling interest.

Yes.

It sounds as if, I just wondered what your other both separately and jointly your interests are?

Yes. I play short mat bowls which is my big interest. I have been very successful at that and I have been playing that since before I met Sharron, since about the age of 12, 13. I enjoy all sports, you know, watching, I do not participate now as much as I would like in a lot of them but I enjoy all sports. Together, we enjoy general things, just socialising with ourselves, going out for a meal, watching television. Going for walks, we are quite lucky where we live; we live on the edge of Dartmoor, so we have lovely countryside around us. Sharron herself, you know, she has interests, she likes being on the computer a lot. Watching television, she reads an awful lot now that her hearing has gone completely. She reads a lot, more than she ever used to and she loves, I know she will hate me for saying it, but she loves cleaning, yes, very strange, but yes she is always, always cleaning. But I think that's quite therapeutic for her.

I wonder how important interests like film, and music and theatre are because I know they could affect enjoyment.

Yes absolutely. Sharron when she had hearing loved music. I think that's been one of the hardest things that has hit her now that she is completely deaf is the loss of the music. We don't have the music on in the house. Certainly not on the music channels on the TV, sometimes I will flick on them for a bit but I know it upsets her when she sees music and we have even got to the extent of removing the stereo from the front room and all the CDs because they just remind her of what she is missing. So that's very hard, because music was a big part of what she liked. As regards to films and so on, yes, we go to the cinema quite a lot.

Because several cinemas show films with subtitles. And because of the deep base and the sound system that is used at cinemas, she says to me sometimes, watching a film you almost forget that you are deaf. Because you can feel the vibrations and the sound in effect. So yes, we love to go to the cinema and we do that as often as we can. And we watch a lot of DVDs at home. So, yes. She has been able to continue doing that because she loves films anyway, so that's really good and I am pleased that worked out.

In a way I think for lots of people technology and that, include DVDs you can watch subtitles, and computers have been –

A big, big help, yes. Yes. I mean, it is, as you say, the technology is helping in all sorts of angles with deafness. And it makes I think deaf people feel more part of the world; rather than yes, isolated.

[19:38]

Yes. I don't know what, I am just wondering what your involvement with LINK has been, if at all? I am not sure.

Yes, we, not long after Sharron was diagnosed with NF2 we went to the intensive course with LINK. I've forgotten what year it was, but it was quite early probably '94 '95 possibly, that was.

How did you find out about it?

It was actually for Sharron's dad we went, he was obviously still alive then. Because we were struggling a lot with communication, we didn't know a lot about the deaf world or the deafened world. So I think that it was the local hospital who knew about it from what I remember back then. So, it was Sharron's dad and mum and myself and Sharron that went because Sharron still had full hearing at that time, so we went for Sharron's dad on the intensive course and wow, that was amazing just to get all this information and learn the stuff it was very good. So that's how we first became involved with LINK.

So, is that I mean because I haven't, although I am on the project, I don't really know much

about how LINK operates actually, so kind of interesting.

I mean, yes. They obviously are a small charity just now combined with Hearing Concern. And they specialise in deafened adults. Yes, I mean back then it was fairly early days and we were up there a little head office in Eastbourne. We went on a specialist week which were for just for NF2 patients only, rather than just the general deafened public. So we met other people who had NF2 which was and we had never met anyone before so that was really good. Most of the staff were deafened. So it was good to see how they worked and coped with NF2. So, yes, they were, I mean the LINK charity were very helpful in all kinds of information like being deafened communication and so on.

At that time you were there mostly for Sharron's dad?

That's correct yes.

She was already aware was she –

Yes, yes. She had known about the NF, so but it was very much of a case she was very fairly young and I have still got hearing so I am not really going to think about it too much. So it was, we went there for our communication with John and also for John to get any help he required. So for Sharron and NF at that point really wasn't a big part of her own life other than obviously being with her dad.

I wonder whether, you know, I would have thought it might have brought it home to her, you know, being in that environment.

Yes, I think she possibly found it perhaps a touch daunting. She's always been a person who has tried to think about anything other than NF and becoming deafened. It was something that she didn't really want to have to deal with. So, she didn't really think about it a lot. That's what she, that was the perception she brought across. It was feeling inside I know she thought about it a fair bit. But she didn't like to show it.

Did she talk to you about it, did you talk together at that stage?

No, not very much. I was quite willing to, but I knew I didn't want to push it too much with her, because I knew that as and when she wanted to talk she would do. So, she was very good at bottling it up at that point. Yes.

Did that have any repercussions later or was it just a gradual kind of acceptance?

It was a gradual acceptance. It didn't have any major effects on us as a couple. I think even at the point, I think leading up to 1999 when she had her first operation to remove a tumour, it was all fine. You know, I just accepted this is what Sharron has, she was worried about would I stay in the relationship. But I was always there and would always give her my one hundred per cent support and I you know told her on numerous occasions that that's how it would always be. So, it was fine up until then. And even with the start of the hearing loss, Sharron had taken lip reading classes and we had been to sign language together. So we tried to do as much as we could as a couple to, you know, support each other in effect. So it has been okay I would say. Yes. Luckily.

[25:02]

Out of interest, have you learned lip reading?

No, well, I tried. Obviously having full hearing it is, I don't obviously rely on it reading that much. Although sometimes if the telly is on at home and the sound is down, I try to watch the lips and there are some things I can pick up. Sharron is very worried about the communication side of stuff when she lost her hearing, but she has actually picked up lip reading very easily. And we use SSE to support our, her lip reading. So, communication is certainly has been a lot easier than I thought it was going to be when she lost her hearing. So, that's been a positive from the situation. Yes.

I think the communication side is very interesting, actually. And would be to anyone.

Yes.

Most relationships people find don't communicate in conventional ways always, so maybe it is just that you –

Yes, it is, was a worry because I think for a deafened person, as you say, communication is very important because you would feel isolated without the communication. And it is obviously nervous talking to new people and just you feel nervous trying to communicate with anybody really. So when you do or when you are able to communicate quite well with some people, you know, mainly your family because obviously if you are communicating a lot with lip reading it is easier to lip read someone who you watch all the time. So, that was I know that was a big worry for Sharron. And there are certain situations now obviously when coming to meet new people and so on, that it is a worry. But yes, the communication was a big worry but thankfully and luckily for us it has been fine.

[27:07]

With your wider family, has communication and support been –

Yes, it has been it, it is quite varied. A lot of people in a situation like this are a bit, will feel nervous hearing people because they don't necessarily know how to communicate with somebody who is deafened. It is the same in my family. My parents are pretty good; they know to talk directly to Sharron and to slow down slightly. There are other members of my family, of course a lot of these people have known Sharron when she had full hearing as well. So it is that transition period has been quite difficult if they don't see her that often. But other members of the family struggle to communicate and forget to look at her, and don't slow down; so, they are all very understanding and very good but it is there is that slight issue of the communication. You know, I have tried to be helpful and tell them how to do it and they start off doing it correctly, but then slip into old ways, yes.

Forget.

Yes, so it can be difficult at times, but Sharron has got the confidence certainly with the family members that we meet to, if she is not sure, she will just ask me what has been said and the family understand that and that's fine. So it has been okay.

[28:34]

Earlier on just now, you talked about the first operation that Sharron had and it was a kind of

crisis at that point?

Yes, Sharron's biggest overall worry with the NF2 and the hearing loss her biggest worry was always facial palsy. I wouldn't say she was extremely vain, but looks are important to her as they are to a lot of people. And obviously people who have facial palsy you are always going to get other people who stare at you and so on, and that's part of society because people don't understand. So, she was very, she was wanting to put off an operation for as long as possible, because she was so worried about facial palsy.

Was it something as you say it might be a very common worry?

Yes.

Is there any counselling or support from the NHS?

Yes, I would say not a great deal. We pretty much have had to do it on our own. The NF Association have support workers which are very few and far between. We did see one who lived in our area, who was very helpful. But the majority of the time it is something you just have to deal with yourselves. Especially as Sharron felt sometimes that she would rather die than have bad facial palsy, which myself and a few of the family you know her mum and so on found very difficult to take, because to me, you know, life is more important. But I understood from Sharron's perspective why she would say that. So that was a big worry. As it turned out, she only had the small over two tumours removed, her facial nerve was kept intact, and with physiotherapy and help at the hospital, she has hardly any facial palsy at all. So, she obviously is very relieved at that. But we are also in a similar situation now with her second tumour, the bigger tumour, is right on the cusp of possibly needing an operation. So that worry is there again with regards to the facial palsy. She has been quite lucky where the tumour hasn't grown in the last five or six years, which is almost unheard of for NF, so we have been very lucky that way. But it is, so it is something that sits on the shelf, and you think about it every 12 months when the scan is due, and the worry is there for us and her. And obviously she gets more anxious and then she will put it away again for 12 months. So an ongoing thing.

I do not know if you have managed to, but I think in a lot of situations like this, it is very

important to kind of live in the present isn't it?

Yes, she tries to do that as much as possible. Yes. I wouldn't say it restricts our lives as they are. Perhaps for future long term plans it is very difficult for us to plan anything to do. So we do, we take it a day at a time and a year at a time and that suits us okay. That is fine for us. But long term plans in anything really, is a bit difficult. Sharron still has not made up her mind of what she wants to do if it gets to that point if she needs to have a second operation. It is something that is on going; we will just have to cross that bridge when we get to it.

Am I right then in thinking if you don't have the operation, when it is considered necessary –

Yes, the pressure of the tumour will push against the brain stem and spinal cord and if it is left she will eventually die if she doesn't have an operation. There could be the thought of having partial removal, but that doesn't always work and the tumour could re-grow. So, yes, if she leaves it, yes it will become too big and she will die.

[33:17]

I mean, do you do much travelling at the moment? Do you or do you - such a beautiful area?

Yes, yes. We do. I travel a lot for work anyway. I drive a lot of miles and through my bowling I have travelled a lot. We, yes, we do like to get away within the country. It is nice living where we do and obviously we live with that day in day out, so it is nice but it is good to get away. Sharron likes to go abroad as well. Obviously we visit my parents in Cyprus. And Sharron's mother and new husband are due to move to South Africa soon. So...

Useful.

Yes, yes and we've got relatives in New Zealand, so we have got some good options around.

And there is no, you don't really need to make any compromises? Concerning travel?

No, no, it is all fine and good.

We started to talk you were telling me about the first LINK awareness.

Yes.

Did any, you know, have there been any follow-ups to that different sort of involvement?

Yes, there have. When we went to the first intensive week it was good and we learned all the new things obviously that we didn't really know. There was not much feedback following that meeting. But then was it last year, no the year before last, Sharron hadn't had a scan for about five or six years, because she had put NF right out of her mind. Okay. That was fine. So, she had got very nervous because she decided to have another scan. So she got herself worked up because she thought that was going to be it, it was going to be time for an operation. Obviously we went and had the scan and she, the news was brilliant that the tumour hadn't grown that much. So that was great, but I think Sharron had been having problems with work; communication with staff, people who she had worked with who knew her when she had hearing, had she become very isolated at work. Because they weren't really communicating or talking to her. So, she decided that perhaps it was perhaps time to go back to LINK to see you know progressions that they had made and communication support and so on, just to refresh our feelings and the information that we could get. So we actually went back on another intensive week summer before last, and, which was a breath of fresh air for us both. One it was good to re-acquaint ourselves with new stuff, see how far LINK had progressed in their course, we met –

How many years was it between the two?

Probably was it '95, so it is going to be 11, 12 years, so a fair time. And it is yes I mean it was absolutely fantastic. We luckily we met some people who are on the, helping on the course, who we had met through the NF Association so we knew a couple of people. But there was some new families there. And we were amazed not only at what we got out of it for ourselves, but how much sharing our experiences with these new people who are in this situation like we were when we first went. And it was amazing to be able to give them a bit of support and help ourselves and it just felt so great and it had given Sharron the push to get her confidence back up again to perhaps look for other work and go from there.

So yes, we did go back and we had good feedback after the week and follow up information is a lot, a lot better now from LINK. So, it was really good and from that we decided that we

would like to help them if we could by becoming outreach volunteers which we now have done.

[37:37]

Okay. Does that mean that you work in your immediate area?

Yes, yes, we cover a fair big area but yes in the south-west for anybody who are newly deafened and their families.

How supportive do you find your, well, I suppose Devon and Cornwall, you know the County Councils? Or is it the NHS Trust but the that sort of level?

The PCT. Yes, to be honest, we don't really use them that much. I think because Sharron has dealt with her deafness pretty well, she hasn't needed that much support. Apart from the problem she was having with work, she had a lot of help from -- I am trying to think what the name is -- Plus, basically they help people in their workplace to sort differences out and give support that way. And she had some help from, that was obviously run by the County Council. And that worked quite well for her to deal with some issues at work.

So yes, I would say that was good. With her health support with regards to her NF we actually travel from Exeter to Cambridge, which is about a four hour trip because Cambridge is a centre of excellence for NF. So Sharron feels she wants the best support so we travel that distance to go. However, they are just trying to start up a centre of excellence in Plymouth which is only 45 minutes drive down the road. Whether we go to there I don't know because Sharron was diagnosed at Plymouth and had a very bad experience with a doctor down there, who did the diagnosis who was very blunt and to the point, didn't really show caring for obviously for a 17-year-old girl whose just whole world was shattered. So, but, yes, so we travel to Cambridge for our health support, so yes.

Okay. I mean, does Sharron or yourself do both of you belong to any like community groups for deafened people?

Yes. No, Sharron did spend some time with a deaf club in Plymouth. I think the problem with that is that is for deaf people who obviously were born deaf. And it is important to

say the fact that the Deaf community and Deaf world is a lot different from the deafened world. Because obviously deafened people had or have some hearing, so she found it very difficult to fit in even with communication, although we know some sign language we are not that brilliant, but use bits. So she found it very difficult to fit into that world. She still sees herself as part of the hearing world.

I think it is my, yes, it seems to me that that is where LINK really, I don't know and Hearing Concern as well I guess, yes it seems to be a very different.

That's why LINK are so important because they just deal with deafened people. And it is totally separate to the Deaf community. It is important to understand that.

I mean, I don't know, but I suspect that the Deaf community are not necessarily that keen to connect with –

No. From my experience, you will find that the Deaf community they have their own communication language, and yes, from my experiences they tend to feel that they are their own separate community. And it is, although it would be good to, you know, merge the two and help each other, they are this, they do feel like they are very separate, in the same way a deafened person feels that they are part of the hearing world, because they have had hearing. So, there is a fairly big bridge there, yes.

[42:02]

Right. I don't know, but I was interested when you said just now about the doctor at Plymouth. I just wondered is there anything more you would like to say about that or was it just –

Yes, sure. Obviously, although Sharron's dad had NF, we knew a little bit about it and had done some research. So, we had a set idea of what things were like. Obviously Sharron was very young, just starting in college. Was looking to become a nursery nurse or a teacher is what she wanted to do. So, we traveled to Plymouth with nervous trepidation because obviously Sharron wanted to know have I got brain tumours or not. It was a Doctor Pobereskin I think his name was, he was an American who actually treated Christopher

Reeves when he had his serious injury when he fell off his horse, Superman, so, yes, so we went to Plymouth went into a meeting room. He was quite abrupt when myself, Sharron's mum and dad all wanted to go in the room together but okay. We pretty much sat down and he said, "yes, you have got brain tumours, we are going to have to take them out and you are going to become deaf". It is pretty much how he said it. And obviously that was a bombshell for Sharron and she became very upset, and it was a very bad experience. And he was fairly perturbed and put out by the way we then tried to ask questions about, you know, radiotherapy. As far as he was concerned, it was his way and that was it. No other options.

You were there at the time, how did he react when he could see visibly how upset she was?

Yes, I think he perhaps felt a bit guilty. I can understand that doctors deal with this stuff every day, every day. And to them it is a job and they, you know, they have to do the job and he's probably been very clinical about the fact that, you know, to save your life we have to take these tumours out. I think he sort of missed the point of the fact there is such a thing as a quality of life as well as a quantity of life. And certainly for Sharron the quality of her life was very, very important. So, yes, I just think he was a bit clinical, that was all. And I think he looked a bit upset and was perhaps a bit ashamed he had said it in the way he had done without thinking about the effect it would have on the family and obviously this young 17 year old girl who was going to college and had the world in front of her.

I would think for her dad it must have been a really difficult time?

Yes, John took it very badly. He only found out about his NF2 after a motorbike accident when he happened to have a scan. And by then he had massive tumours. So he didn't really know he had it. And at that point obviously he had already had the two children; he took it very badly that he felt very guilty that he had passed this thing on. Especially after his doctor in Exeter seemed to think that it wouldn't happen and it would be fine. So then to find out that both Sharron and Sean had had NF he took it quite badly and also Sean, Sharron's brother, took it extremely badly and did for a certain amount of time blame John for it. You know. That is just how he reacted to it.

[46:01]

How is Sharron's brother now, what stage?

Sean was in the navy, and was obviously when he was diagnosed he, after a few years, he was taken out of the navy with his hearing decreasing slightly. As I said earlier, his tumours weren't quite as big as Sharron's; he is, well he was married, but has now divorced but he has four children. It has been - Sean is, has been very much, NF, I am not dealing with it at all. Don't even want to think about it. He has tried to live a normal as much a life as he can. Obviously now Sharron and her mum, who are very close and Sharron's mum has always had problems with Sean from being a teenager upwards, they never really got on. But they have got that worry about the four children now obviously. Sean has met a new partner called Angie, she is very supportive and very good. The good thing is obviously now the testing of the children is very, could be a very young age and they keep an eye on it and it is much better than it was than when Sharron and Sean were diagnosed. But, yes, Sean has lost a fair bit of his hearing now. I haven't seen him for many years and Sharron has only seen him a couple of times because he lives up in Hastings. So we don't see them that often, so...

What about his four children, is it too young for them to be –

The oldest two have had scans, but we haven't heard back. I think it is probable that Gemma has got NF, she will now be coming up to I think she is now about 15 now, 16, which is still, you know, quite young and it can be dealt with. So, it is difficult to really say much more than that because we don't see him that often, yes.

[48:18]

I mean, I don't know if you want to talk about this at all, I just wondered have you considered having children?

Yes, we have talked about it several times. We made a decision between ourselves several years ago that because it is a 50-50 chance of passing on the condition that we wouldn't have children. At this current moment I, regardless of NF, I don't want any children. And myself and Sharron were of the same opinion. However recently, I think Sharron would like to have a child now. I think that's a lot to do with the progression of the detection of NF. So it feels

like it can be managed much more now. So, I mean I am 32 now.

I was going to say how old is Sharron?

She is 31. So perhaps a bit of time left but I am still of the opinion that I just don't want to have children. But that might change.

Sure. Is there anything you know that you would like to talk about that we haven't talked about or anything you would like to you feel you didn't have a chance to kind of finish talking about?

Well, only perhaps really just a small bit about being a deafened partner rather than the actual deafened person.

For myself, personally, this has been a part of my life and it is something that I deal with okay. I think it is important to realise that there are people out there who must remember it is not always about the deafened person. A big part of their communication loss and their having lost their hearing has an impact on family and you know partners. So, I think that's part of the reason we have taken on the outreach volunteer role, is that I myself can be there specifically for families and partners to give them advice, because obviously they will be suffering as well.

Have you found in reality that that has been a really –

Yes, yes. I mean, because I hate to say it, I feel I deal with it quite well myself. So I am perhaps a bit lucky, but I have met other people who really struggle with dealing with their partners or their children who are deafened. Because there is not a great deal of support out there. Obviously LINK do a brilliant job, but getting it across can be difficult which is why the outreach volunteers are so useful. So, I want to certainly make that a big part of any volunteering and if I meet people that's what I want to do, is make sure that the families that are partners get the support that they need as well as the deafened person, yes. Yes.

So, that's usually directed, that's a very specific audience who are deafened and have partners and/or partners and children?

Yes, it is. I mean, I also think myself and Sharron have been talking about making sure that we try and spread the word about the difference between being deafened and being deaf and two worlds and we really want to try and in our local area look at NHS and support groups. For instance, it is amazing the amount of times you go into an Audiology department and you will be waiting for an appointment, but you can't hear very well and they will just stand there calling your name. So to help train people in Audiology departments and places like that. Just to give a bit of feedback to them and how to communicate and what it is like I think it is something we are quite passionate about doing.

Yes, you are right. There is a lot to be done and I think there is a lot to be done just in the general community.

Yes, absolutely.

There is real lack of awareness and I am myself, I include myself in that as well.

Yes, you will know, yes.

But okay. I think we could bring the interview to an end if you are happy?

Yes, happy.

You have been very eloquent.

No problems.

So I will bring the interview to an end now. Thank you, Simon, very much.

Thank you, Pam.

For participating and Mirella, thank you very much. I will stop it.

[End of recording]